

In the first part the SPARE RIB Cancer Series, JO SPENCE dealt with her rejection of orthodox treatment for breast cancer, and her moving into alternative therapies. In the third and final part of our series, she expands on some of the themes of that article, raising some important questions about illness, and giving practical information on where to look for treatment.

A PICTURE OF HEALTH

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I offer here some questions and ideas for consideration. Some of these came up during the course of orthodox treatment, some afterwards during my investigation and moving into, then enjoying, my new health regime. I would emphasise that I have found no evidence to contradict the notion that cancer is a complicated process to reverse or rid ourselves of, and whatever is offered here is merely information, not a way for anybody else to proceed. If women decide to combine orthodox and supplementary treatment they will of course be supervised by a doctor. But if, as in my case, there is a rejection of orthodox medicine, it is still nonetheless vital to be supervised at all times by a qualified medical practitioner. Because the treatment I chose, traditional Chinese medicine, is still in its pioneering days in this country (though it is regularly used in China), it is not easy to have access to a network of practitioners. I was lucky in that I found a practice where they were willing to take me on as a patient, in spite of the fact that it is illegal for anybody who does not have an orthodox medical qualification to treat cancer.

However, as they are not treating the cancer, but my entire condition, this seems to be a way round the double bind that those of us who wish to choose to proceed outside the NHS are in. Of course there are private health insurance schemes which one can negotiate with to have a range of treatments for cancer, but as I am opposed to this in principle, I have had, of necessity, to find a way to move forward outside the NHS, whilst operating on a very low income. Because I am a socialist I support the idea of a national health service within a welfare state, but because I am also a feminist I will fight with others against patriarchal medicine as it is currently practiced in this country. Also, concentrating on the whole woman is in no way in opposition to group struggles over the social and political causes of illness.

In using the term 'orthodox' throughout, I mean the dominant system of medicine as practiced within the NHS. In using the term 'supplementary' I mean the other sixty six therapies which exist in the private sector which need to be paid for, but can be used in combination with orthodox medicine. In using the term 'alternative' I mean all therapies which are practiced outside orthodox medicine, most of which have to be paid for.

PATIENTS' RIGHTS

Before you go to a doctor or to hospital it is important to know that you have the right at all times to refuse treatment (unless you are considered to be insane, suffering from an infectious disease, or considered incapable of looking after yourself). A patients' rights leaflet is obtainable from the National Consumer Council, from Citizens' Advice Bureaux, or from your local Community Health Council.

You have the right to ask that a friend or partner of either sex be present during examination or consultations. You have the right to refuse to sign a 'patient consent' form if you are not happy about surgery offered to you.

We should have the right to know not only 'side effects' and survival rates for treatment but also what non orthodox therapies, or complementary treatment is available on the NHS. (Important to note that the Homeopathic Hospital in London offers orthodox treatment for most cancers, although iscador (mistletoe) injections are considered suitable for some types of breast cancer.

If opting for mixed treatment (i.e. orthodox and complementary therapies as in combination), it is important to establish with your doctor that this is YOUR decision and you don't expect it to be undermined in subtle (or unsubtle) ways.

You do have the right to know if you are part of a 'trial' in which pairs of patients are double-blind computer matched via their similar symptoms and then each given different treatment, which is monitored. There are at least six major trials going on in this country in different regions. What does being part of a 'trial' mean in relation to your right to make decisions about your own body? I was (unbeknown to me) part of a trial in the Nottingham area and was never told until I attended another hospital who 'didn't believe in such trials'.

We should have the right to know that different consultants actively oppose each other's treatment for the same set of conditions (in some hospitals mastectomy is still fairly automatic, in others not so, sometimes consultants in the same hospital have different methods of treatment).

You should make it clear if you wish to refuse to have your disease progressively documented by a medical photographer for use as teaching materials, lecturing, the writing of papers or the illustration of books (most consultants ask to have two sets of slides done of 'interesting cases' - one for the patient's records and one for their own private collection). Why don't we document our own health, keeping an inventory of all chemical intake throughout our lives - this is often requested of you if you decide on a naturopathic detoxination programme.

Try to keep copies of all letters you handle which are about you (open them - nobody can do much about it). Ask for the right to read your notes and ask as many questions as you feel you need to. There are 'management techniques' for handling awkward patients - try to watch how you are being 'handled' if you are not too frightened. Some people have even managed to make tape recordings of their consultations which are very useful later for a variety of reasons.

Try to get advice from the welfare rights people on the difficult decision of whether to sign off from work (or unemployment) as 'sick' or not, which often mucks up payments to you for weeks on end. Also whether or not to have the disease named on certificates (do you want personnel to have you marked out as a potential health risk)? Part of the whole syndrome of the 'victim hiding the problem', also linked to the compulsion for you to conform and wear a prosthesis after removal of a breast. To get rid of the evidence of what has been done to you.

You should have the right to know just what your NHS doctor is 'allowed' to prescribe for you if you opt for supplementary alternative therapies which

include massive doses of vitamins or minerals. The MIMS guide to prescribable medicines is held by all pharmacies and you can ask them to look things up for you. In my experience, the nearer a patient is perceived to be to death the more likely the G.P. is to cooperate with complementary prescriptions.

If you are interested to know your rights in relation to making decisions about your death then contact the Euthanasia Society. Far too much fear around breast cancer resides in our inability to face the fact that either the disease or the treatment might kill us.

SOME BASIC PROBLEMS

If you suspect that you may have lumps in your breasts but are afraid to go for immediate screening it might help to visit a naturopath and go onto a very strict cleansing diet for four to six weeks. This may clear up non-malignant lumps and might mean the avoidance of an awful lot of pain and anguish.

The breast screening process will not indicate your general bodily condition, nor the presence of other tumours. If disease is fairly advanced then the lopping off of a breast will hardly help the overall condition. Other testing and screening is sometimes done after an operation, but not always. Beyond that you are recalled for regular breast screening, but the rest of your body is ignored until something manifests itself as a symptom.

It is important to consider the cost effectiveness, from the state's point of view, of NHS treatment. Removing a breast is often cheaper than 'staging' the treatment (i.e. removing lump, then radiotherapy, then perhaps chemotherapy). Not only is it cheaper to have body bits removed but it is often considered unimportant for women to want to 'cling to' their ovaries, wombs and breasts once they are past child-bearing age. Often different treatment is offered to younger women.

Beyond breast screening, hardly any hospitals do any follow up work for breast cancer patients once you are 'cleared', and there is no notion of the prevention of recurrence. Most people go back to exactly the same circumstances as brought them there in the first place. Then we hope for the best, or live in terror of the next outbreak of our bodies. Why are we not encouraged to try to help ourselves more? Six monthly screenings won't encourage us to change the circumstances of our daily lives.

BOOKS AND PAMPHLETS

A GENTLE WAY WITH CANCER, Brenda Kidman, Century Publishing, 1983.
BREAST CANCER - a guide to its early detection and treatment, Carolyn Faulder, Virago, 1982.
THE BIRTH OF THE CLINIC, Michel Foucault, Tavistock, 1973.
THE BRISTOL DIET, ALEC FORBES, M.D., Century Publishing, 1984 (essential reading for all cancer patients).
CANCER IN BRITAIN: the politics of prevention, L. Doyal (and others), Pluto Press, 1983.
THE CANCER JOURNALS, Audre Lorde, Sheba, 1985.
THE CANCER SYNDROME, Ralph W. Ross, Grove Press Inc., New York, 1980.
THE DOCTORS ANTI-BREAST CANCER DIET, S.L. Gorbach, D.R. Zimmerman and Margo Woods, Simon & Schuster, 1984.
GENTLE GIANTS, Penny Brohn, Century, 1986.
ILLNESS AS A METAPHOR, Susan Sontag, Penguin, 1983.
IT MAKES YOU SICK: the politics of the NHS, Colin Thunhurst, Pluto Press, 1982.
LET'S GET WELL (and other titles on vitaminology, diet and health) by Adele Davis, Unwin Paperbacks, 1979.
ORTHODOX CANCER TREATMENT, a critical analysis of results, research and clinical practice, a pamphlet written and self published by Jean Walton. (Most of the data referred to is drawn from research done on breast cancer and the writer has gone back to original data on survival figures for women WHO HAVE HAD NO TREATMENT AT ALL, and re-interpreted the overall survival figures and come to some astonishing conclusions. The report has been examined by the Director of the South Western Metropolitan Cancer Registry who has been unable to quote any unfairness or bias in the new interpretation made of old research). Jean has given me permission to supply xerox copies to anyone interested (s a e).
OUR BODIES, OURSELVES, ed Angela Phillips and Jill Rakusen (Penguin £4.50).
THE OTHER MEDICINES, Richard Grossman, Pan, 1986.
THE TOPIC OF CANCER, when the killing had to stop, Dick Richards, Pergamon Press, 1982.
WHOSE BODY IS IT? The troubling issue of informed consent, Carolyn Faulder, Virago, 1985.

More and more evidence is being accepted that cancer is a systemic disease (i.e. the entire system is involved). If this is so, and we are not merely a set of signs and symptoms which can be read off tumours and cell conditions, how is it possible to talk of breast cancer as a killer? The term is inaccurate and misleading. Women do not die of lumps in their breast, they die because there co-exists with lumps other conditions, either in the lymphatic system, or in other parts of the body. Some breast cancers are slow or fast growing, others are already linked to lymphatic cancer - how can we begin to educate ourselves to look for a fuller and more long term view of the disease?

When you go into hospital a brief history of family health patterns is usually taken (which in my experience is never referred to again). How can we seriously talk about hereditary tendencies between generations of women? As the non orthodox have pointed out we inherit diet and stress patterns and patterns of repressive, 'being good' behaviour as women, which are as important as any genetic structures. How can we de-naturalize what seems to be a common sense view of breast cancer, and feel it is possible to change our lives to be different from previous generations of women? Long term depression is the norm for breast cancer patients, treated with mood-changing drugs, yet other forms of therapy would be far more effective in helping us to change our lives.

It is generally accepted by alternative therapists (and in particular the Gerson therapy) that chemotherapy or irradiation can prejudice your chances of survival. If you opt for orthodox medicine and it fails you, and you then turn to alternative therapies your chances of survival will be jeopardised by the previous treatment. It is important to bear this in mind from the very beginning when trying to sort out the best way to proceed through treatment. Once the immune system has been broken down it is very difficult to build it up again so that it can help you survive.

In all cancer treatment it is really important to emphasise **MANAGEMENT** rather than 'cure'. As diabetics take daily precautions to keep their bodies in a state of dietary balance, so most non orthodox regimes strive in the long term to balance the mind and body for optimal functioning. If this balance is lost then the physical or mental state deteriorates again (in any number of ways) as the body moves into 'disharmony' and illness.

What is the importance of nutrition to breast cancer? Firstly it has been found that low animal fats are helpful, and secondly that excess weight is detrimental. On a fruit, vegetable and grain diet weight

just drops off until the body finds its own optimum weight. Dieting in this sense is nothing to do with calorie counting but is about maximal nutrition from minimal intake. For those of us who are compulsive eaters we have to do work on the emotional roots of our eating problems, so that we can actually enjoy new eating habits, rather than experience them as a continual misery.

ALTERNATIVE APPROACHES TO SURVIVAL

If you have been told you have cancer I feel it is important to read all the **POSITIVE** stuff on how to survive you can get your hands on. Reading death statistics will cripple you emotionally unless you somehow manage to turn it on its head and say to yourself, 'I intend to be a survivor'. Alternative bookshops are good stockists of books and pamphlets on alternative health and critiques of orthodox medicine. If you can't afford to buy the stuff, once you have located it then you can order it from a library. If you are reading for 'prevention' of cancer then the order in which material is read seems to me to be very different and might even include quite a lot about orthodox practice itself.

You need to cold bloodedly sit down (on your own or with an ally) to work out what resources you need, what you can afford, what you will have to ask to be given, and what dearly held previous beliefs about yourself and your invulnerability as super woman will have to be examined pretty quickly. Also finding a strategy for letting others know you have needs so perhaps theirs will need to be deferred for a while!

In the hospital where I was, all the women were going straight back to their jobs and/or looking after their families as if nothing had happened. The turn round time for mastectomy then was three to four days if all went well.

Such needs might include the following:

- a network of support (even if such a network doesn't perceive of itself as such).
- Some kind of counselling (some regions have voluntary counselling schemes through the hospitals, or else these can be located through **CANCERLINK**).
- Money! You need to maximise your resources and assets.

If you feel you want to investigate alternative approaches to breast cancer, to try to put together a 'package deal' for yourself, which might consist of orthodox treatment, plus (say) acupuncture or diet, then this is relatively easy to do if you

have an income of your own. This can be high on impossible for working class women who are on low incomes or whose income becomes part of the family income, and who anyway, are more used to 'doing what the doctor says', and perhaps less articulate in a situation where they are in a sub dominant position. The Bristol Cancer help Centre is a mine of information here.

All alternative therapies have to be paid for by somebody. Many practitioners have a sliding scale of charges. Within whole body, or holistic medicine, this would include preventative/curative treatment in the form of herbs, acupuncture or naturopathic treatment, change of diet, and various forms of exercise. It would also involve looking at the psychological side of our lives and perhaps going into some form of therapy. Most therapies cost money, though some less than others (co-counselling for instance costs little to learn and nothing to practice, beyond your own time and commitment). 'Therapy' is much more likely to be on offer if you are middle-class, whereas chemical drugging and/or psychiatric treatment will be seen as 'solutions' for working class-women.

In alternative cancer therapies there are various approaches - all of which aim to build up the immune system. These range from mucousless diets, Gerson detoxification therapy, nutritional therapy, vitamin C therapy, to the system I opted for in traditional Chinese medicine. I have listed some institutional bodies and books which I feel would be useful to help you deal with these various approaches.

Perhaps you will decide that you want a non invasive form of diagnosis. Iridology is the reading off of your bodily conditions from colour configurations within the eyeball and iris. I have given details of their association in the resource section.

Try to think of your body as your major resource in life. Do you want high technology which attacks the system like a war machine, or low technology which helps to convince the body that you are willing to listen to its warning signs, and to care for it better. (Read Rachel Carson's 'Silent Spring' for analogies with the maltreatment of the land by 'experts').

It is very important to understand the difference between the terms orthodox/nonorthodox and supplementary/alternative medicine. Especially their complications in relation to:

a) How do you get access to monitoring resources at low cost or no cost if you opt for alternative treatment? It is usually assumed that most people who purchase their health care are rolling in money. If you don't want to run the gamut of hysterical consultants every time you refuse their treatment, where do you go then?

b) There may be problems with certification for absence from work for the recovery period after operations/treatment, or for long periods off work. Only a registered doctor is legally entitled to treat cancer, therefore if going to an alternative practitioner how do you describe the illness? Important to know how to get invalidity benefit from the DHSS if you are entitled to it. Long term illnesses can qualify for payment at a higher rate than normal sickness benefit, but who is qualified to sign the certificate?

I feel it is important to think about different holistic health approaches as SYSTEMS. Western medicine treats all other systems as commodities, i.e. they will lift a bit off the shelf and insert it into their own system of medicine. There is a constant struggle going on for definitions of health care between orthodox and non orthodox practitioners, as to who will have professional status, who can prescribe treatment, who can be employed by the state as part of the NHS - but eg India and China each have their own philosophies of medicine, and medical sub cultures. When looking for treatment for cancer I feel it is useful to know how other cultures have dealt with it - not all miracle drugs are seen as miraculous in other cultures, though some have revolutionised health care.

It is important to know where to get information about alternative approaches - lists included of professional bodies in Resources.

We should realise that if we opt for alternative treatment for cancer this means alternative treatment for everything, including headaches. Herbal and non chemical remedies are readily available in most towns from registered herbalists. If we opt for alternative treatment what do we do in emergency situations?

It is important to know how to separate the disease from its treatment. Possibly getting in touch with others who have gone the alternative route will help. (I did it by putting a letter into the magazine HERE'S HEALTH which brought forth dozens of replies. They also list health groups in various towns).

There are sometimes problems of how to deal with secondary infection after treatment or operation. Because the immune system is invariably damaged by orthodox medicine, or because it is actually dealing with fighting the disease, the rest of the body is much more prone to anything else going wrong. Often people coming out of hospital after surgery have a major round of colds, flu, shingles, etc. If they are also dealt with chemically it compounds the problem. If undergoing radiotherapy then large doses of Vitamin C are said to help the side effects.

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HINTS FOR THE DAILY ROUTINE

How can you evolve methods of stopping people treating you as a victim or a heroine? Telling you shock/horror stories of other people's cancer and treatment? Initially when I was ill people were in full flight with their anecdotes before I could stop them. The images of horror and death piled up at an alarming rate and it was only when I went to Bristol Cancer Help Centre that I realised the importance of having positive (even Utopian) images to aspire to.

If you are on a strict diet then it is important to find strategies to stop other people encouraging you to break it. Most people's notion of a diet is in relation to calorie control, which is different. How do you persuade friends it is not a social disaster or failure on their part to serve you baked potato and salad while others gorge themselves! At home I was lucky because my partner offered to share my new eating habits.

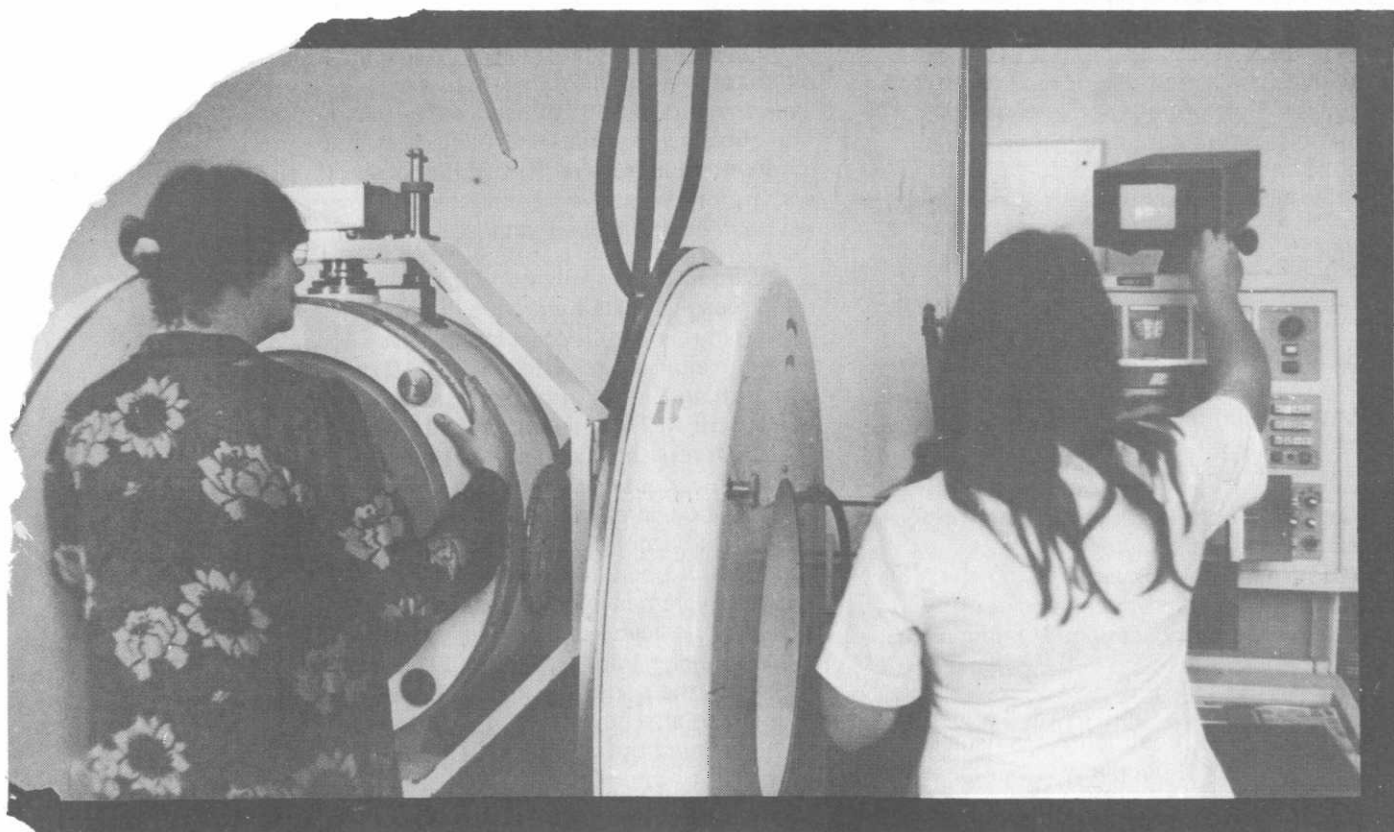
Think about the problems of meeting others who have the same or similar problems to you. Do you want to mix with people who are having orthodox treatment (this often happens in a therapy group) people who are trying to combat degenerative illnesses in general who have a good pool of information about systemic diseases (eg. multiple sclerosis, arthritis)? Do you want to meet survivors or people already half dead with chemicals?

Important not to become under nourished and anaemic through very strict forms of dieting and detoxification. This must never be undertaken lightly or without qualified supervision. (Vegans have provided a lot of literature about this - see Resources.

It is important to know where to buy food in bulk, and survive on a low income-especially sprouting grains and seeds for alive food with maximum nutrition

If you opt for a new cleansing dietary regime then you need to reorganise your kitchen so that you have everything you need to hand, including herbs and spices for flavouring. If you intend to carry on with a mixed kitchen (i.e. cook one diet for yourself and another for others) then this needs to be thought through. If you intend to strive for a different attitude to health this will include new patterns of food preparation and eating, so you might as well get used to it from the beginning. If you have had bouts of compulsive eating throughout your life (as I had) re-organization also makes life a lot easier. It is useful to colonize existing cookery books, especially vegan and vegetarian, as most so-called health diets are very bland. Also read cookbooks from other cultures

If you change your diet suddenly to one which is mostly fruit and vegetable then your internal eco-system of stomach and intestines will feel like a battlefield, with excessive production of body gases. Very



embarrassing and uncomfortable initially, and you can't tell if you are getting better or worse!

There is a need for some sort of assertiveness training for those of us who feel totally intimidated by the medical profession

CONSCIOUSNESS RAISING

How do we deal with the abject loneliness of the long struggle for health (the most boring of subjects to other people who are 'well'). How to present yourself as a subject in daily struggle. People are used to the 'narrative resolution' of illnesses like cancer (in the media's terms you are either, 'dead' or 'better'. The actual STRUGGLE over many years to regain health is not good box office). It is more like soap opera with its continual peaks and troughs and minor resolutions for most of the time.

Cancer may mean restructuring your life AND society, but when you as an individual have it, the struggle is usually on your own! You have to get your priorities sorted out - if you are a feminist or a socialist it probably means that you are involved in half a dozen struggles which are no longer IMMEDIATELY relevant to your day to day life. Cancer research and 'self love' must take priority in my opinion at this stage. This can cause a lot of internal conflict if not sorted out from the beginning. (I lay in bed worrying that I could not go to a rally at Greenham the day before my operation!). The amount of solidarity among people around cancer is very limited (and breast cancer terrifies most women) - and though people are 'supportive' - they can't take on our burden for us. It is often up to very close friends and/or, our partner to shoulder the main burden with us. But what do we do if a partner rejects us because our 'body image' is no longer tenable to us or to them through having breast cancer? Who do we turn to?

A basic problem for me as a socialist feminist was that I had a 'conflict' model of the world. How to mesh this up with needing to be more 'harmonious' in order to begin to be well again. For instance, initially I took on the medical profession rather than the illness itself!

How do you deal with the problem for us as 'new' women of 'over performance' in order to prove ourselves, often burning ourselves out? (Something I continue to witness to my horror)

How do you deal with your own bravado/rebellion? Being the 'naughty little daughter' is all very well when facing up

to doctor/daddy, and nurse/mummy within the cancer field (where most top jobs are held by men) but what we need is knowledge of how to begin to take responsibility for ourselves and have a say in defining our own bodies. A well trod path in feminism but not in relation to breast cancer.

The problem of love and sexuality for us in relation to this particular illness? How to redefine 'love' and move towards a less phallogentric type of sexuality. Many women see their sexuality as totally destroyed through mastectomy and hysterectomy... a good prosthesis might help us to pretend to the world that nothing has happened, but for many women the scars will remain in memory long after the others have faded. Good counselling can help here.

Time scales? If it took twenty years to get your body in the state it is now, then how can you expect a few 'magic bullets' to sort it out. We need a different philosophy of our body's needs in relation to cancer therapies. It might take many years to get the body back onto an even keel - it might never do it. But, as has been said times, the 'quality of life' may be vastly improved.

Not only is there a 'cancer industry' where (as in America) more people are involved in researching and treating the disease (and whose standard of living may depend on it) than are actually being treated at any one time, but it is important to note the continual orchestration in the national media of various 'break throughs', 'miracles', 'new discoveries' (always on the horizon) etc. The public relations of the British Medical Association is quite phenomenal, and this orchestration should be examined for its sub text in the ways in which it constructs 'the truth' of cancer. In an inverse ratio to this is the limited mileage given to alternative (and less miraculous and more long winded treatments) in its onslaught against the cancer orthodoxy.

Some people have theorized that cancer is just another form of slow suicide. Whilst this might be highly contentious I feel that for some people life might be so stressful and apparently unchangeable that legalized death is the only way out. However, in my own journey through illness I seriously considered my rights to suicide or euthanasia and found the literature of the Voluntary Euthanasia Society very useful

Finally, and on a positive note, I feel it is IMPORTANT to try to help others to share a new philosophy of health. My partner, David, asked if he could attend the same practice as me, which he now does. I am quite happy that our general health is openly discussed between all of us, and that he is taking the same long term (good ecology, whole body, MIND and body INTEGRATION) route as myself. ♀

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A full resource list of organisations, reading material and addresses relating to cancer and alternative treatments is available by sending a large SAE to Jo Spence, 651a Harrow Road, Wembley, HA0 2HA Middlesex.

The list covers Books and Pamphlets, Magazines, Buying of Supplies, Useful Cookery Books, Information Services in Relation to Cancer, Dying and Death, Complementary Medicine, Nutritional/Naturopathic approach to Chronic Illness, and General Health Information.

This article is the third in a wide-ranging SPARE RIB series on Cancer. The first part of Jo Spence's article is in SR163. In SR164 Kit Mouat looked at the control of cancer treatment by the medical establishment and the drug industry.

If you missed either of the previous articles, send £1 for one issue or £2 for both issues (incl postage) to Spare Rib Back Copies, 27 Clerkenwell Close, London EC1 OAT, enclosing your name and address, and stating which issue you require.

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